STATEMENT OF

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SENIOR ASSOCIATE LEGISLATIVE DIRECTOR

PARALYZED VETERANS OF AMERICA

BEFORE THE

HOUSE COMMITTEE ON VETERANS' AFFAIRS

CONCERNING

THE DEPARTMENT OF VETERANS AFFAIRS

MEDICAL AND PROSTHETIC RESEARCH PROGRAM

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Mr. Chairman and members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to testify today on the Department of Veterans Affairs (VA) Medical and Prosthetic Research program. Research is a vital part of veterans' health care, and an essential mission for our national health care system. PVA is very involved in many aspects of medical and prosthetic research because of the long-term impact that these initiatives can have on our members.

We understand that this hearing will address three focus points: (1) the relevance of VA research to the clinical treatment of veterans; (2) two special research projects—the OIF/OEF initiative and genomic medicine—identified in the FY 2007 budget submission; and (3) the need for upgrades and modernization of VA research facilities. We will address each of these points individually.

The VA health care system is a unique environment combining clinical care, education, and research. VA currently supports approximately 3,800 researchers at 115 VA medical centers. The research program serves as an excellent recruitment tool for young doctors as well as scientists because it gives them an opportunity to develop skills as clinical researchers. According to the VA, nearly 83 percent of VA researchers are practicing physicians. Because of this dual role, VA research often immediately benefits patients. For example, functional electrical stimulation, a technology using controlled electrical currents to activate paralyzed muscles, is being developed at VA clinical facilities and laboratories throughout the country. This technology is now being applied to many PVA members receiving health care service and rehabilitation therapy at spinal cord injury centers. Through this technology, tetraplegic patients have been able to grasp objects, stand and pivot to assist transfers, and control bladder function. We anticipate greater capacity for even walking short distances.

Within the VA's Office of Research and Development are two services that directly support the importance of VA research to clinical treatment of veterans. The Health Services Research and Development Service (HSR&D) projects are multidisciplinary activities that involve expertise in a combination of clinical fields—physicians, nurses, therapists—as well as social sciences—psychology, sociology. Ultimately, the underlying objective of health services research in VA is to understand and improve clinical decision-making and care.

The Clinical Sciences Research and Development Service (CSR&D) conducts clinical trials and epidemiological research on key diseases that impact veterans. CSR&D research project accomplishments include key research findings across a range of diseases and definitive evidence for clinical practice.

Through the system's scope of primary, secondary, and tertiary care, as well as long-term care, with multi-disciplinary academic affiliations, the VA brings validation and innovation to the delivery of the best care for today's veterans. Perfect examples of this idea are the Parkinson's disease Research Education and Clinical Centers (PADRECC) and Multiple Sclerosis (MS) Centers of Excellence. These centers represent a successful strategy to focus the Veterans Health Administration's (VHA) system-wide service and research expertise to address two critical care segments of the veteran population. They integrate direct health care services, education, and research to the benefit of veterans in the system.

Since 1997, PVA has worked with VA MS clinicians and administrators, as well as with private MS providers and advocates to address the then 'patchwork' service delivery by VHA towards veterans with MS. While we identified the scope and range of VA's patchwork of MS services, it became very apparent that vital elements indeed existed; if only they might be brought together in mutual support of VA's mission to serve MS veterans.

The designation by VA of two MS Centers of Excellence located in Baltimore and Seattle/Portland represents "centers without walls" engaged in marshaling VA expertise in diagnosis, service delivery, research and education and making the same available across the country through a 'hub and spokes' approach. The mid-term evaluation of these two centers very positively acknowledges the success of VA's strategy.

Regarding the PADRECC's, PVA recognizes again that these centers are a specific approach to give VA a focus for health care service and research. The treatment breakthroughs, including very delicate surgical procedures, of recent years must be localized so that they might best be assimilated into VA-wide practice. PVA supports this approach for both Parkinson's disease as well as Multiple Sclerosis. We would urge the Committee to consider legislation which would permanently authorize these centers because they represent the true value of VHA as a national health care system success story.

Likewise, since 1976, VA has built a system of Geriatric Research, Education, and Clinical Centers (GRECCs) in anticipation of the impact of the aging of World War II and Korean War veterans on health care needs and delivery. The system has grown to 21 centers in 19 of the VA's 21 Veterans Integrated Service Networks (VISNs). In 2005, the GRECCs accounted for nearly 10% of the VA's total research activity, expending over $100 million investigating the diseases, disabilities and rehabilitation needs of elderly veterans and developing and testing innovative approaches to care for them. Almost $80 million of that came from outside the VA. GRECCs provide advanced clinical expertise for caring for some of our most medically complex and frail veterans. They have developed, tested, and disseminated numerous clinical innovations. They are responsible for training almost 2/3 of the doctors specializing in geriatric care in the United States. Perhaps most importantly, because of the GRECCs research productivity, they actually return to their host VISNs across the entire VA more capital than they cost the system.

Noteworthy recent accomplishments of these cost-effective geriatric centers of excellence are too numerous to list in full, but a few examples are offered to provide an indication of the scope and range of GRECC contributions. GRECC researchers at the Puget Sound, Minneapolis, New England, Ann Arbor, and Madison GRECCs have dramatically advanced the understanding of Alzheimer's disease, the molecular mechanisms of brain destruction, who is at risk for it, how to identify those at risk, how that risk may be modified, and models of care in the home and in institutions for those who are affected. GRECC clinician-scientists at Baltimore, Cleveland, Miami, Pittsburgh and Palo Alto have explored new approaches to rehabilitation strategies for those afflicted by stroke, trauma, and neurological diseases like Parkinson's Disease, multiple sclerosis and myasthenia gravis—employing a wide range of strategies including regeneration of nerve and muscle tissue, electrical stimulation and computer-assisted limb prostheses, innovative exercise regimens, and lifestyle and environmental modifications. Other sites have made similar

dramatic strides in addressing spinal cord injury care, end of life care, cancer regimens, the aging immune system (including the recent introduction of an effective vaccine against shingles), medication use, mobility, urinary dysfunction, swallowing disorders, hearing and speech disorders, arthritis, osteoporosis, and thyroid disease.

The budget submission includes plans for two special research projects to begin in FY 2007. The first project focuses on the special needs of service personnel returning from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF). The project envisions a wide ranging number of research efforts, including targets in post-traumatic stress disorder and other mental health issues; amputation and prosthetics research; and returning personnel reentry and reintegration. We appreciate that even as the VA begins to move forward with this project, it is already collecting data to determine if the health care needs of amputees and severely injured veterans from OIF and OEF are being met and to identify areas where improvement is needed. This data will help focus the project on additional areas that need to be studied.

This project would directly support the important role that research plays in the clinical setting. Through this project clinicians would learn and apply new tools to the treatment of physical and psychological conditions experienced by the men and women returning from the Global War on Terror. Furthermore, findings from this research project will be shared with Department of Defense (DOD) treatment facilities, particularly Walter Reed Army Medical Center and Brook Army Medical Center, as well as the Defense Advanced Research Projects Agency.

As a member of the Friends of VA Research (FOVA) coalition, we wholeheartedly support the vision to expand the VA research program to encompass the needs of service personnel returning from current conflicts, whether they include polytrauma, massive burn injury, or mental health conditions. Such expansion of the program requires new resources so that VA's other research areas, which are equally important to the long-term care of veterans, do not suffer.

PVA believes that this project could be paired with Amputation and Prosthetic Centers of Excellence as introduced in legislation in the Senate (S. 2736). As we stated with regards to the Parkinson's disease and MS Centers of Excellence, the VA has the essential expertise to focus dedicated services on a wide range of medical conditions. Through research and clinical trials, it can then transfer learned approaches for specific care to the broader VA health care system, and ultimately, throughout the entire medical world. The Senate legislation calls for the creation of these focal points and the need for resources to actuate that goal. We must emphasize, however, that additional real dollars will likely be needed to establish these centers. PVA believes that these centers could be the spearhead for research and development of evidence-based performance test standards for amputee and prosthetic devices.

The second special research project would focus on genomic medicine. The thrust of this project is to link veterans' genetic information with the VA electronic health record. The budget submission states that "the goal is to develop genetic assessments that will potentially enable 'mass customization' of medical treatment." The program will ultimately allow clinicians to make better decisions for veterans based on their genetic information. Furthermore, it will address patients' rights, informed consent, privacy, and ownership of genetic material involved with genetic tissue banking. We believe that the human genome reports of recent years have

provided a strategy to integrate clinical symptomology with genetic testing to create a predictive model that could extend health care delivery to a truly preventive service.

PVA recognizes the fact that, much like the greater VA infrastructure, research facilities are aging and in need of repair or renovation. For decades, insufficient construction funding has been provided to maintain, upgrade, and replace VA's aging research facilities. The result is a backlog of research sites that need major and minor construction funding. Moreover, researchers are often limited by the lack of state-of-the-art facilities. And yet, VA clinicians and researchers still need laboratory space, clinical settings, and record keeping. These three elements need to be as current as possible.

Five years ago, the VA received $25 million specifically for upgrades and enhancements to research facilities. However, no specific funding has been provided since. We appreciate this Committee and the House of Representatives earmarking $12 million for minor construction for VA research facilities this year. However, a steadier stream of funds must be provided. Sporadic funding does not enable the agency to plan appropriately for either on-going research or new initiatives. We urge Congress to begin investing dedicated funding into the rapidly deteriorating infrastructure in which VA clinicians and researchers conduct their activities.

The VA has informed FOVA that it would need three years to complete a research facilities assessment before it could invest new money into its research infrastructure. However, an assessment was just completed in 2003. That assessment could be used as the baseline for a faster reevaluation so that much-needed upgrades are not held hostage to this process.

PVA believes that one particular change could be made that would allow the VA to invest additional resources into its infrastructure. Currently, many VA researchers are primary grantees from the National Institutes of Health (NIH). However, these researchers do not receive any additional funding to support indirect costs of their projects. Indirect costs include infrastructure that the VA researchers use to conduct their work. This seems to be inherently unfair and needs to be changed.

In conclusion, our greatest concern with the Medical and Prosthetic Research program is chronic under funding. VA research has been grossly under funded in comparison to the growth rate of other federal research initiatives. Although the Administration's Budget Request called for only $399 million for this account, we appreciate the efforts of the Committee to provide additional funding to the program. However, we believe more can be done. In accordance with the recommendations of *The Independent Budget*, we believe that the Medical and Prosthetic Research program requires $460 million. This would allow the VA to expand the scope of many of its research projects and begin upgrading and expanding its research infrastructure.

Mr. Chairman, PVA appreciates your continued interest in maintaining a viable research program. We look forward to working with the Committee to ensure that adequate resources are provided for Medical and Prosthetic Research. Quality research outcomes can only lead to better patient care for veterans.

Thank you again. I would be happy to answer any questions that you might have.

Information Required by Rule XI 2(g)(4) of the House of Representatives

Pursuant to Rule XI 2(g)(4) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2006

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $252,000 (estimated).

Fiscal Year 2005

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $245,350.

Paralyzed Veterans of America Outdoor Recreation Heritage Fund – Department of Defense – $1,000,000.

Fiscal Year 2004

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $228,000.

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Carl Blake is the Senior Associate Legislative Director with Paralyzed Veterans of America (PVA) at PVA's National Office in Washington, D.C. He is responsible for federal legislation and government relations, as well as budget analysis and appropriations. He represents PVA to federal agencies including the Department of Defense, Department of Labor, Small Business Administration, and the Office of Personnel Management. In addition, he represents PVA on issues such as homeless veterans and disabled veterans' employment as well as coordinates issues with other Veterans Service Organizations.

Carl was raised in Woodford, Virginia. He attended the United States Military Academy at West Point, New York. He received a Bachelor of Science Degree from the Military Academy in May 1998. He received the National Organization of the Ladies Auxiliary to the Veterans of Foreign Wars of the United States Award for Excellence in the Environmental Engineering Sequence.

Upon graduation from the Military Academy, he was commissioned as a Second Lieutenant in the United States Army. He was assigned to the 1st Brigade of the 82nd Airborne Division at Fort Bragg, North Carolina. Carl was retired from the military in October 2000 due to a service-connected disability.

Carl is a member of the Virginia-Mid-Atlantic chapter of the Paralyzed Veterans of America.

Carl lives in Fredericksburg, Virginia with his wife Venus, son Jonathan and daughter Brooke.